MEDICAL RECORD

Information Practices

(Complete Form Only On Initial Visit)

(301) 496-3331

We, here at the Clinical Center (CC), strive to provide privacy for all our patients and to maintain the confidentiality of the sensitive personal information they share during the course of treatment. As stated in the Patients' Bill of Rights, "The patient has the right to privacy concerning the medical program. Case discussion, consultation, examination, and treatment are confidential and will be conducted discreetly. The patient has the right to expect that all communications and records pertaining to care will be treated as confidential to the extent permitted by law." Sound policies and procedures have been put in place at the CC to support these efforts while not excessively inhibiting the traditional, open exchange of information upon which the research mission of the National Institutes of Health (NIH) rests. However, there are usual and unavoidable risks to confidentiality to be found in any health care organization and, while we will do our best, we cannot guarantee absolute and total confidentiality for any patient. Therefore, if you believe that information about you is of interest to the media, or that you are otherwise particularly vulnerable to the release of some sensitive personal information, you should discuss the matter in depth with your Patient Representative, who can be reached at 496-2626.

The collection, maintenance and use of patient information in medical records or other data storage systems at the CC is governed by the Privacy Act of 1974, The Freedom of Information Act and the Public Health Service Act. Under those laws and implementing regulations, employees of the NIH and the Department of Health and Human Services may have access to any information necessary to perform their assigned duties. In addition, there are certain statutory exceptions and published routine uses of personally-identified information that do not require prior approval for release to individuals or organizations that are not a part of the NIH. Those are discussed at length in the Patient Handbook under Section 2: "Patients' Rights, Informed Consent, Confidentiality." In brief, they are:

- 1. Physician(s) or organization(s) identified by the patient shall receive ongoing medical updates.
- 2. The Social Work Department may share information to assist patients in the community.
- 3. The Travel Office may inform public carriers of patients' special requirements, such as wheelchairs.
- 4. Information regarding diagnostic problems or having unusual scientific value may be shared with consultants.
- 5. Information may be shared during audits of the operation of the CC.

Authorization for Release of Information:

- 6. Congress may request information for matters within their jurisdiction or on behalf of constituent patients.
- 7. Certain diseases or conditions, including infectious diseases, may be reported to appropriate representatives of State or Federal Government as required by law.
- 8. Information may be released for statistical analysis without personal identifiers.
- 9. Contractors may require access to certain information in order to provide a service. In such cases, all contractor personnel shall be subject to the requirements of the Privacy Act.
- 10. Information may be released to facilitate the defense of a federal employee involved in a law suit.
- 11. The Bureau of the Census or the National Archives may request records for survey, census or historical preservation.
- 12. Information may be released in response to a court order or for law enforcement purposes.

Except for the uses described above, medical and personal information about a patient is not given to anyone without the specific written permission of the patient. However, there is one additional exception: if at some later time, a hospital or physician who is caring for you needs information immediately, and if waiting to obtain your permission could endanger your health, the information will be released immediately, and you will be notified of the release by letter. Information may be transmitted via facsimile unless you specifically prohibit that means of transmission.

The following individuals or offices stand ready to assist you with many aspects of information practices at the Clinical Center. Please do not hesitate to contact them if the need arises:

Medicolegal Section:

Media Interaction and Policy:Breach of Confidentiality:Special Privacy Requirements:	CC Communications: Privacy Act Coordinator: Patient Representative:	(301) 496-2563 (301) 496-2292 (301) 496-2626	
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I have read this explanation of information practices at the CC and have been given the opportunity to discuss it and ask questions. Furthermore, I understand that if I have any questions or concerns about the use of information at the CC, I may contact any of the persons or offices listed above for assistance.

Signature of Patient/Normal Volunteer or Parent/Legal Guardian for Minor	Date
Signature of Witness	Date

Patient Identification

Information Practices NIH-2753 (10-99) P.A. 09-25-0099 File in Section 4: Authorization